



Generic quality of life utility measures in health-care research: Conceptual issues highlighted for the most commonly used utility measures

Suzanne Pietersma · M. Elske van den Akker-van Marle
Marieke de Vries

Abstract:

Purpose. Effectiveness of health interventions is often measured by means of generic utility measures (e.g., EQ-5D). These measures focus on aspects of QoL that can be expected to be affected by health-care interventions. We argue that traditional health-related utility measures are based on a relatively narrow focus on the concept of QoL. Therefore, to better judge the effectiveness of health interventions, measures need to go beyond traditional health-related QoL utility measures.

Methods. We conducted an analysis of the definitions and questions of the five most commonly used generic utility measures: the EQ-5D, SF-6D, QWB-SA, HUI2 and HUI3.

Results. Traditional health-related QoL utility measures are based on a relatively narrow focus on the concept of health and health-related QoL. We illustrate this narrow focus by zooming in on two issues: a) the focus on a too selective number of domains; and b) the use of a narrow interpretation of the features that can be part of domains.

Conclusions. We believe that using insights from different backgrounds and research fields (i.e., the subjective wellbeing approach and capabilities approach) will result in a more complete operationalization of health and health-related QoL and hence will ultimately facilitate the allocation of health-care resources to interventions that are most effective in increasing people's (health-related) QoL.

Keywords: quality of life, health care outcome assessment, medical economics, subjective wellbeing, life satisfaction

1. Introduction

Valuing the effectiveness of health-care interventions can help the allocation of scarce health-care resources by maximizing health benefits. Effectiveness of health-care interventions is nowadays most often measured in terms of quality-adjusted life years [1,2]. Quality-adjusted life years combine the quality and quantity of life into a one-dimensional outcome. Commonly used scales to assess quality of life (QoL) are generic utility measures, like the EQ-5D, SF-6D and HUI [3]. These QoL measures provide valuations (i.e., utilities) for different levels of a predefined set of domains, such as pain and mobility. They focus on domains of QoL that can be expected to be affected by health-care interventions and are therefore often labeled as health-related QoL measures. A common critique is that such utility measures do not capture all domains relevant to QoL [4]. That is, the focus in health-related QoL utility measures is



mainly on physical functioning and not that much on domains related to people's mental and social experiences or adaptive capabilities. For example, existing health-related QoL measures mainly focus on grasping the physical effects of cure-related treatments and do not detect important effects of health interventions in medical contexts such as end-of-life care [5,6]. Besides the critique on existing QoL utility measures there is also a shift in the way health is perceived. That is, the original definition of health of the World Health Organization (WHO) is said to be insufficient in these days – there is a need for an increased focus on people's capabilities [7,8]. Amid all these developments we want to reflect upon the content of traditional health-related QoL utility measures. Is it true that traditional utility measures are not capable of grasping all essential QoL domains? In the current article we will zoom in on the definitions and questions of the five most commonly used generic health-related QoL utility measures: the EQ-5D, SF-6D, QWB-SA, HUI2 and HUI3 [3,9-11]. We argue that traditional utility measures are based on a relatively narrow focus on the concept of health and health-related QoL. Consequently these measures a) address only a selective number of domains of QoL and b) oftentimes interpret (some of) these domains in a restricted fashion.

Besides focusing on these two issues we also briefly underline the potential usefulness of combining a diverse spectrum of theoretical ideas about QoL, wellbeing and health. That is, we will highlight insights from not only the utility background [12], but also from a psychological subjective wellbeing background [13,14] and the capabilities approach [15,16]. We believe that using insights from these different backgrounds and research fields results in a more complete operationalization of health and health-related QoL; and hence may ultimately facilitate the allocation of health-care resources to interventions that are most effective in increasing people's (health-related) QoL. This article is not meant to be a complete overview of all practical and theoretical issues related to QoL utility measurements. Our key objective is to highlight the narrow focus of the five most commonly used health-related QoL utility measures and show the relevance of different theoretical insights in the light of the altered perception of health; i.e., health revolves around people's abilities and resources to autonomously cope with life's ever changing physical, mental and social challenges [7].

2. Generic QoL utility questionnaires – too selective number of domains

First of all we wanted to see what is meant when people say that utility measures do not grasp all domains relevant to QoL [4]. In unraveling this issue we noticed that all five traditionally used utility measures have a common conceptual framework. They are all based upon the general WHO definition of health [17-22]. That is, there is a degree of consensus within the field of population health around the three-dimensional conception of health offered by the WHO – "Health is a state of complete positive physical, mental, and social wellbeing and not merely the absence of disease or infirmity" [23]. This definition covers both the absence of negative aspects as well as the presence of positive aspects. Perfect QoL is equivalent to health in all three domains. However, the WHO definition is perceived as too broad and general [22,24]; thereby creating the necessity of formulating more concrete working definitions and operational definitions. Consequently the translation of the WHO definition to concrete scales results in many variations [22] and leaves ample room for incompleteness in QoL measures. We wanted to determine whether or not the three building blocks of health – physical, mental and social health – are represented in the existing scales. Next, we will illustrate that the five most commonly used health-related QoL utility measures employ a narrow focus; we looked at the working definitions and scale items of the five measures (see Table 1 (below) for an overview).

Table 1. Content of the five most commonly used generic utility measures: the EQ-5D, SF-6D, QWB-SA, HUI2 and HUI3

Utility Measure	Working definition	Operationalization of working definition
EQ-5D	People’s overall perceived health status	Questions on physical domain dominate (3 out of 5 items)
SF-6D	People’s overall perceived health status	Exclusive focus on physical and mental domains [18]
QWB-SA	Health is perceived as the absence of functional limitations and/or specific symptoms and problems	Questions on physical domain dominate (66 out of 74 items)
HUI2/HUI3	Health is perceived as the absence of functional limitations and/or specific symptoms and problems	Exclusive focus on physical and mental domains [21,29]

The QWB-SA, HUI2 and HUI3 formulated a quite limited working definition; health is perceived as the absence of functional limitations and/or specific symptoms and problems [20,21,25-27]. Functional limitations could refer to all three pillars of health. They can refer to people’s physical symptoms, but also to daily problems people experience due to mental problems (such as anxiety issues) or social problems (such as having a limited social network). In general, however, when QoL measures refer to functional limitations they most frequently refer to physical problems or symptoms [22,28]. In the QWB-SA this strong focus on the physical pillar of health is underlined by the concrete operationalizations of the working definition. That is, the QWB-SA contains almost exclusively questions referring to physical domains (e.g., symptoms, self-care, mobility, physical activity). In the HUI the strong focus on the physical and mental pillar is underlined by the additionally used ‘within the skin’ working definition of QoL. This means that the focus is exclusively on mental and physical aspects; social aspects are considered ‘outside the skin’ [21]. The exclusion of the social component is also shown by statistical analyses: the HUI3 does not adequately measure social functioning [29].

In comparison, the EQ-5D and the SF-6D have broader working definitions. That is, people’s overall perceived health status is central. Not only dysfunction is central, but also function [17-19,30]. In the working definitions no selective reference is made to a subset of the three WHO pillars of health. However, when looking at the operationalizations of the working definitions it becomes apparent that in both scales not all three pillars of health are equally represented. In the EQ-5D the questions on physical functioning and disabilities (i.e., mobility, self-care, pain/discomfort) dominate. One question assesses the mental health pillar (i.e., anxiety/depression) and one question is aimed at assessing the social health pillar (i.e., usual activities). For the SF-6D the overrepresentation of the physical and mental domains is explicitly noted by Ware [18], who states that the “third factor in the WHO physical, mental, and social conceptualization of health remains to be operationalized” (p. 338). In sum, the five most commonly used generic utility measures focus predominately on the physical health pillar of the general WHO definition of health, leaving the other two pillars underrepresented.

3. Generic QoL utility questionnaires – narrow interpretation of domains

In analyzing the content of the five utility measures we focused not only on the number of domains included but also on the interpretation of the meaning of the domains of QoL. The three pillars of health in the WHO definition can be interpreted in different ways. As stated earlier it is argued that the current focus of the WHO definition should be changed [7,8]; it is argued that a focus on people's abilities and resources is more fruitful than is a narrow focus on people's perceived decrease in functional abilities or perceived physical state. A broad focus on people's abilities and resources makes it possible to capture to what extent people are able to autonomously cope with life's ever changing physical, mental and social challenges. Abilities and resources can be defined as people's adaptive qualities, self-management skills and coping abilities. The focus is on how well people are able to cope with diseases or impairments and not on reduced functional abilities. The reasoning is that people's ways of adjusting to changed circumstances or functional abilities is more important than whether or not people have a measurable change in health status due to a certain chronic or acute disease [7,8]. Next, we illustrate how the five most commonly used generic QoL measures employ a narrow interpretation; the focus is almost exclusively on people's functional abilities.

As described above, the QWB-SA, HUI2 and HUI3 are based on a working definition of health that exclusively focuses on functional limitations and/or specific symptoms and problems [20,21,25-27]. No reference is made to people's ability to cope and adapt. Although for the EQ-5D and the SF-6D the working definition is broader [17-19,30] than the definition used by the previously mentioned measures, their operationalizations still strongly focus on people's health status. First of all, in the EQ-5D and the SF-6D the questions on physical functioning and disabilities dominate. In addition, the questions related to the mental pillar do not focus on people's mental abilities or resources. The focus is on functional mental issues or problems, such as depression and anxiety disorders. In the EQ-5D the same reasoning applies to the social pillar: the question posed focuses on problems in performing daily activities. That is, the focus is on functional limitations and not on people's coping abilities or adaptive qualities to handle daily struggles. In sum, the most commonly used generic utility measures include questions that focus extensively on 'objective' functioning and not that much on people's coping abilities and resources. That is, existing utility measures focus on people's actual level of functioning (i.e., whether or not people are still able to walk) instead of focusing on how people cope with changes in their physical health (i.e., whether or not people find ways to get by in daily life despite changes in physical health).

4. Consequences of a too-strict definition of health – cure versus care

Before elaborating on potential ways to achieve a broader outlook on QoL in utility measurements we first want to illustrate the effects of using existing generic utility measures. To this end, we looked at the usefulness of current generic utility measures in the cure versus care sector. In the cure sector the focus is on health gains; that is, on curing diseases. The main focus is on people's degree of physical functioning and on eliminating diseases. It can be deduced that the physical and 'objective' orientation of generic utility measures could be sufficiently equipped to capture such effects of interventions in the cure sector. However, also in the cure sector it is well possible that mental and social domains as well as adaptive responses and coping abilities of people have a strong influence on their QoL, hence making the physical and 'objective' orientation used in generic QoL utility measures too narrow. This problem is even more predominant in the care sector. This sector is concerned with chronic diseases, which nowadays in Western societies are most prevalent and account for most of the

expenditure in the health-care system [7]. The care sector is not that much focused on eliminating diseases, but more on regulating or reducing the effects of long-term limitations on people's daily activities. The main aim is to increase wellbeing in general and not only to create physical and functional health gains. Interventions in the care sector are concerned, for example, with living with diabetes or with end-of-life care. The focus is more strongly on people's experiences and their adaptive capabilities. Consequently, it is expected that the 'objective' orientation used in the generic QoL utility measures is too narrow [31,32]. A broad outlook (i.e., looking at all three pillars of health as mentioned in the WHO definition) and a focus on resources and abilities are essential, especially for the care sector, to capture the effects of health-care interventions as fully and correctly as possible.

5. Theoretical ideas about QoL

The focus of traditionally used QoL utility measures can be seen as being too narrow. A clear and solid theoretical model of QoL would help in constructing broad generic utility measures of general QoL. There are some general theoretical frameworks related to QoL. However, there is no consensus in the scientific literature on the ultimate theoretical framework [33,34,40]. This lack of clarity in the theoretical underpinning of QoL leaves ample room for incompleteness in generic QoL measures. We believe that using insights from different backgrounds and research fields will provide promising suggestions for improving health-related QoL utility measures.

There are two other research approaches, beside the utility approach, that are frequently mentioned when it comes to capturing the important aspects of QoL [40], namely the subjective wellbeing approach [13,14] and the capabilities approach [15,16]. Subjective wellbeing is a central concept in the psychological realm. In this field QoL is typically described as subjective wellbeing, happiness or wellness [13,14,35-37]. Broadly stated, wellbeing concerns how people think and feel about their lives. It concerns affective and cognitive evaluations. Both positive and negative experiences are included. Satisfaction with a diverse array of domains is central to subjective wellbeing; such as satisfaction with work, leisure, family, social relationships, mental health and physical health [13,14]. The focus is explicitly on mental and social domains; that is, the focus is on the two pillars of the WHO definition of health that are underrepresented in existent utility measures. In addition, people's subjective experiences, abilities and feelings are central. The objective 'correctness' of people's experiences is not relevant. In addition, the capability approach of Amartya Sen can be seen as a philosophical theory [15]. The capability approach provides a general framework of QoL that revolves around people's abilities or inabilities to achieve certain end states given their resources. The theory concerns the freedoms people have in life. Sen explicitly states that the focus should not be on people's functioning but on people's capabilities [15,16] – this matches the new suggested definition of health mentioned earlier (i.e., concentrate on people's coping abilities) [7,8]. The capabilities approach has often been linked to health-related QoL research; it is seen as a framework that is able to fill gaps in the field of health-care assessment [16].

Both approaches (i.e., the subjective wellbeing approach and the capabilities approach) are in accordance with the newest suggested definition of health [7,8]. That is, both approaches provide a concrete framework that matches the new definition of health; they provide a characterization of a generally agreed upon direction in which to look in order to translate the new definition to concrete scales that capture QoL more comprehensively. We believe that both theoretical approaches provide complementary and promising perspectives that are pre-eminently qualified to enrich and broaden existing health-related QoL utility measures. Until now, there has not been, unfortunately, very much cross-fertilization between the utility

approach, subjective wellbeing approach and capabilities approach [38-40], likely because they all originate from quite separate fields. We opt for closer collaboration between all three research disciplines to create solid definitions and operationalizations of health-related QoL.

6. Theoretical ideas about QoL –missing links

Although we believe that using insights in the field of QoL utility measurement related to subjective wellbeing and capability is fruitful, neither approach can be simply and directly incorporated in QoL utility measurements. Each approach can be defined as a general theoretical framework. That is, they do not provide clear cut operational definitions and consequently there is no universal concrete operationalization of QoL or wellbeing. In the psychological realm there are hundreds of different scales in use that are based on the broad conceptualization of wellbeing [41]. The domains included in these wellbeing questionnaires differ greatly. In addition, in Sen's view the operationalization of QoL depends on the exact research question; thus there is no universal operationalization of QoL [15,16]. Consequently, based on both the subjective wellbeing approach and the capabilities approach, it is unclear which aspects are missing in any given traditional QoL utility measures. Thus, besides the need for consensus on a general theoretical view of health there is also a need for consensus on a matching conceptualization. More debate and research is needed to clarify these issues before both the subjective wellbeing approach and the capabilities approach can be applied in expanding or adjusting existing health-related QoL utility measures.

7. Necessary future steps

Besides these specific theoretical issues there are also some more general matters that need to be resolved in order to develop new or altered utility measures. We will highlight two important issues. First, utility measures can include only a limited number of questions/domains. That is, only a limited number of items can be added to utility measures if the measure is to remain usable. Second, including diverse domains in one scale can create problems (e.g., objective versus subjective items; proximal versus distal items; specific versus abstract items). For example, subjective items require totally different answering options and instructions than do objective items, creating a scale that is cognitively demanding. Moreover, including both specific and abstract questions in one scale can cause the problem that the specific items are part of another larger and more abstract domain.

New or altered utility measures can be developed in many ways. A possible route could be first to undertake a Delphi-study amongst scientific experts to determine what the essential domains of QoL are. By including scientists from diverse disciplines, insights from different theoretical angles (e.g., subjective wellbeing approach, capabilities approach) could be included. The next step would be to construct concrete questions that capture these domains and to test those questions in a large sample of respondents. For example, one could test whether/which domains overlap and how the domains correlate with different existing QoL/wellbeing measures to determine which domains have the greatest validity in capturing the physical, mental and social phenomena of QoL. This would enable researchers to identify a small selection of QoL domains and to solve many practical and theoretical issues (e.g., level of abstractness).

We believe that a utility measure should capture physical, mental and social domains to an extent sufficient to create a comprehensive operationalization of QoL. This will ultimately facilitate the allocation of health-care resources to interventions that are most effective in increasing people's (health-related) QoL in relation to the cost of doing so.

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Authors

Suzanne Pietersma
Leiden University Medical Center

M. Elske van den Akker-van Marle
Leiden University Medical Center
vandenakker@lumc.nl

Marieke de Vries
Tilburg University

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